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Adapting an Autism Screening Tool for Use in the DeKalb County Refugee Pediatric Clinic

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Abstract

Background—Minimal literature exists regarding Autism Spectrum Disorder (ASD) among refugee children in the United States. Reliable ASD screening tools, such as the M-CHAT-R/F, have yet to be culturally adapted and translated into some languages spoken in the homes of these children.

Methods—Pediatric refugee patients (n = 13) of caregivers of Bhutanese (Nepali-speaking) descent were screened using a newly translated Nepali M-CHAT-R/F. The M-CHAT-R/F was adapted based on feedback from Bhutanese caregivers and interpreter expertise. Qualitative interviews regarding caregiver awareness of ASD were conducted.

Results—Caregivers understood the majority of M-CHAT-R/F items (91%). Four items required revision. Interviews revealed minimal awareness among Bhutanese caregivers regarding ASD or child development.

Discussion—The M-CHAT-R/F was adapted into Nepali using a combination of translation protocols, and is publicly available for clinical use. Future validation studies are needed which will aid in clinical screening for and epidemiologic research of ASD in this population.

Keywords

Autism; M-CHAT-R/F; Refugee; Bhutanese; Nepali

Conflict of interest All authors declare that they have no conflict of interest.

Ethical Approval The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

Background

The Centers for Disease Control and Prevention (CDC) estimated that in 2010, Autism Spectrum Disorder (ASD) affected 1 in every 68 U.S. children, though the prevalence appears to vary across geographic areas and among racial and ethnic groups [1, 2]. Although ASD is considered a lifetime diagnosis, recent literature is clear that early detection of ASD, when followed by a combination of mental health, behavioral and educational therapies, provides children and caregivers with optimal skills to live with ASD [3]. However, access to these therapies can be dependent upon a diagnosis of ASD; thus, timely evaluation is crucial for families caring for children with ASD [4].

The Modified Checklist for Autism in Toddlers, Revised with Follow Up (M-CHAT-R/F) is a free tool that is available online and has been translated in to many languages; as such, it is widely-used in clinical settings across the world [5]. The M-CHAT-R/F is a two-stage ASD screener, which has been validated as an ASD screening tool among low-risk toddlers [6]. The first-stage questionnaire, the M-CHAT-R, consists of twenty yes/no items that are designed to be answered by the child's caregiver in a primary care setting [6]. In the event that a child screens positive using the M-CHAT-R questionnaire, additional follow-up questions (M-CHAT-R/F) are used by healthcare providers to improve the specificity of the screening tool, thus decreasing the number of false positives [6].

Awareness, screening, and diagnosis of ASD within the US and other high-income countries continue to improve; however, there remains little knowledge regarding the prevalence of ASD and research on ASD within US immigrant and refugee populations [7]. In fact, the global medical community's knowledge of ASD is based almost entirely upon research and epidemiologic data from high-income countries [8]. Not only is the medical community's knowledge of ASD in the refugee community scarce, but refugee caregivers' knowledge of developmental milestones and delays is often inadequate [9]. The combination of these gaps in knowledge may very well contribute to the known disparities in time to diagnosis for developmental disabilities that exist among refugee and immigrant communities [7]. These disparities may be exacerbated by physicians' tendencies to underdiagnose ASD within ethnic minorities [10]. Therefore, it is imperative that healthcare providers are properly equipped to screen for ASD within refugee communities.

Although the original M-CHAT has been translated Into many languages, the context of the questionnaire's items may not be culturally appropriate for children raised outside of the US or by caregivers with different cultural backgrounds, thus requiring appropriate cultural adaptation(s) of the screening tool [11, 12]. For example, validation studies in both China and Mexico required cultural adaptation of the M-CHAT before validation of the screening tool could occur [13, 14]. Other studies reinforce the notion that without appropriate cultural adaptation, the M-CHAT's international use is limited [15]. Despite the necessity of appropriately adapted screening tools, a recent review of ASD screening tools demonstrated that the cultural adaptation process often fails to follow recommended translation guidelines [12]. Without an ASD screening tool properly adapted for refugee children, pediatricians caring for this population remain ill-equipped to screen for, and thus appropriately care for refugee children affected by ASD.

The Modified Checklist for Autism in Toddlers, Revised with Follow Up (M-CHAT-R/F) is a free tool and is widely-used in clinical settings, both internationally and domestically; it is available online and has been translated into many languages [5]. The M-CHAT-R/F is a two-stage ASD screener, which has been validated as an ASD screening tool among low-risk toddlers [6]. The first-stage questionnaire, the M-CHAT-R, consists of twenty yes/no items that are designed to be answered by the child's caregiver in a primary care setting [6]. In the event that a child screens positive using the M-CHAT-R questionnaire, additional follow-up questions (M-CHAT-R/F) are used by healthcare providers to improve the specificity of the screening tool, thus decreasing the number of false positives [6].

Georgia ranks 8th among US states for refugee resettlement, with the vast majority of new refugees resettling in DeKalb County [16]. Since 2001, DeKalb County has resettled approximately 17,000 refugees, more than one-half of all refugees that resettled in Georgia during this time period. More than 3,000 of these refugees are Nepali-speaking, Bhutanese in origin [9–11]. Bhutanese refugees are the second-largest refugee community in Georgia, composing almost twenty percent of the state's entire refugee population from 2004 to 2015, out-numbered only by Burmese refugees [17]. The Refugee Clinic at the DeKalb County Board of Health provides health screening for the majority of new refugees entering the county, and the DeKalb County Refugee Pediatric Clinic (DCRPC) is available to provide well and acute care for newly resettled refugee children. Per recommendations of the American Academy of Pediatrics and as required by Medicaid, ASD screening occurs at the 18 and 24 month well-child visits at the DCRPC using the M-CHAT-R/F questionnaire. Translations of the original M-CHAT or the more recent M-CHAT-R/F are used when available; however, the M-CHAT-R/F is not available in the two languages most commonly spoken by the children and families who receive care at the clinic (Burmese and Nepali). When translations of the questionnaire are not available (as is the case for Burmese or Nepali speaking families), clinic interpreters translate and administer the questionnaire to caregivers verbally in real-time. Thus, M-CHAT-R/F translations not only utilize valuable translator time, but may also be subject to variability among interpreters.

The objectives of this project were two-fold: (1) translate and adapt the M-CHAT-R/F for use as a culturally appropriate screening tool for Nepali-speaking, Bhutanese refugee children, and (2) conduct brief, open-ended interviews with Nepali-speaking Bhutanese caregivers to better understand their knowledge of child development and ASD.

Methods

Participants

A total of 13 refugee children and their caregivers, who were Bhutanese in origin and Nepali-speaking, participated in the study between June and July 2014. Eligibility criteria included children of Bhutanese Nepali-speaking caregivers, aged 16–30 months, who had no known diagnoses suggestive of developmental delay.. Caregivers were all native Nepali-speakers, although many of the caregivers reported at least some English-speaking ability (see Table 1). Caregiver literacy, both in Nepali and English, was assessed by caregiver report. Caregivers reported either poor, fair, good, or excellent Nepali literacy; English literacy was reported as some English, proficient English or fluent English (i.e. bilingual).

Seven children were recruited using the DCRPC patient database. Caregivers of eligible patients were contacted by phone and asked to bring their child to the DCRPC for a well-child check and/or ASD screening. Six additional children in the local refugee community were identified by the clinic's primary interpreter. Caregivers were contacted, who agreed for the children to be screened during home visits (see Fig. 1). Caregivers received a \$25 gift card for their participation.

Overview of Study Design (see Fig. 2)

Our study design, which is later described in more detail, can be summarized by the following steps:

1. Initial forward translation of M-CHAT-R/F into Nepali.
2. Primary modifications of the initial forward translation are completed. Patients 1–6 are screened with the newly modified M-CHAT-R/F.
3. Secondary modifications are implemented into M-CHAT-R/F. Patients –13 screened with the M-CHAT-R/F using secondary modifications.
4. Final back translation of the Nepali M-CHAT-R/F into English.

Note that short, open-ended questions were asked of caregivers regarding their knowledge of ASD and child-development in conjunction with M-CHAT-R/F screening.

This project was made possible by funding from Emory University's Boozer-Noether scholarship and the Emory Global Health Institute. The project proposal was submitted to the Emory University Institutional Review Board, the Georgia Department of Public Health, and the CDC Scientific Determination Process and was determined to be non-research/public health practice, and thus, exempt from IRB review.

M-CHAT-R/F Translation and Adaptation

Note that *translation* refers to the process of translating written text from one language into written text in another language, while *interpretation* refers to the oral process of translating spoken word from one language into spoken word in another language. For our purposes, a certified Nepali translator provided the initial forward translation of the M-CHAT-R/F into Nepali. Two certified Nepali interpreters worked to interpret caregiver and provider discussions in the clinical setting.

The M-CHAT-R/F was chosen for translation and adaptation because it is a validated, free, easily accessible, and widely-used ASD screening tool with high sensitivity and specificity in the population in which it was validated [6]. After written permission to translate the M-CHAT-R/F into Nepali was granted from the questionnaire's author, we began our four-step translation process: forward translation, primary modifications, secondary modifications, and back-translation. This process, which was modeled after the World Health Organization's (WHO) translation and adaptation protocol [18], began with a forward translation of the M-CHAT-R/F into Nepali, completed by an American Translator Association certified Nepali translator. Prior to the next step in the translation process (primary modifications), an expert panel was convened with the primary purpose of

providing information regarding ASD and the M-CHAT-R/F to the clinic's interpreters prior to screening patients and adapting the M-CHAT-R/F. The panel consisted of ASD experts from CDC, the lead pediatrician at the DeKalb County Refugee Pediatric Clinic, the M-CHAT-R/F translator, two DCRPC Nepali interpreters, and the medical student-author. Next, primary modifications to the initial forward translation were made by a second certified Nepali interpreter with considerable experience working at the refugee clinic. These modifications simplified language that was found to be overly formal and/or literal. During the M-CHAT-R/F screening process, the initial M-CHAT-R/F questionnaire created by these primary modifications was used for screening in the first half of patient interviews (with patients 1–6). However, secondary modifications, made by two experienced certified medical interpreters, were recorded—but not implemented—during this time. These secondary modifications were based on the interpreters' linguistic and cultural expertise, as well as feedback provided by Bhutanese caregivers. Secondary modifications were then incorporated into the questionnaire at the project's midpoint and implemented during the second half of the study (patients 7–13). Lastly, a final back translation was provided by a bilingual speaker, unaffiliated with the refugee clinic, whose native language is Nepali.

The M-CHAT-R/F follow-up questions were later translated by a certified Nepali interpreter. Due to limitations of caregiver time and interpreter funds, these follow-up questions underwent one forward translation only.

Patient Screening & Caregiver Interviews

The M-CHAT-R/F was administered to the caregivers, either at the DCRPC or in the community setting. A certified medical interpreter was present for all caregiver verbal interviews. In the event that the caregiver was unable to comfortably read the M-CHAT-R/F, the interpreter read the translated M-CHAT-R/F verbatim. Literate caregivers completed the Nepali M-CHAT-R/F questionnaire themselves.

The M-CHAT-R/F screening consisted of two steps which were implemented for each questionnaire item in tandem. This step of “cognitive interviewing” is in keeping with the WHO translation and adaptation protocol [9]. For each M-CHAT-R/F item, the caregivers were first asked to answer the item with a “yes” or “no” using the modified M-CHAT-R/F. Next, the caregivers were asked several open-ended questions, which were designed to (1) determine the caregiver's level of understanding of each M-CHAT-R/F item, (2) discover Nepali words or phrases that were inappropriate and/or difficult to understand in the context of the questionnaire, and (3) provide suggestions for improved wording or phrasing of the M-CHAT-R/F items. To accomplish this, caregivers were asked to explain each M-CHAT-R/F item in their own words, to specify words or phrases that were difficult to understand, and to offer suggestions to clarify the questionnaire's language.

Following the completion of this two-step process for each of the M-CHAT-R/F items, caregivers were asked three additional open-ended questions. These questions were asked orally by the clinic interpreter and were selected by the author consensus with the objective of providing insight into the caregivers' understanding of the overall purpose of the M-CHAT-R/F within the clinical context, as well as the caregivers' knowledge of child development and autism. These questions included, “Why do doctors ask these questions

[referring to the M-CHAT-R/F] about children?” “What does the term ‘child development’ mean to you?” and “Have you heard of the term autism? If yes, what does it mean to you?” Caregiver responses were recorded using an iPhone® recording application and subsequently transcribed verbatim for further review by the authors.

Data Collection

Although this study was determined to be IRB exempt, and thus did not require caregiver consent. However, the authors felt that the process of obtaining consent would demonstrate respect on behalf of the authors, especially since caregivers’ answers were being recorded. Written consent was offered to every caregiver; however, several caregivers declined to sign the written consent form and opted for verbal consent only. Caregiver interviews, including both the M-CHAT-R/F screening questions and follow-up open-ended questions were recorded using an iPhone® recording application. Identifying demographic information was not recorded via the iPhone® recording application. The English translation of the caregiver interviews were transcribed verbatim by the authors immediately following the interviews.

Analysis

Following de-identification of the interview transcription, an ASD expert from the Centers for Disease Control & Prevention assessed the transcriptions for caregiver understanding of each M-CHAT-R/F item. To do this, caregiver responses to the prompt “explain the [M-CHAT-R/F] item in your own words” were assessed to determine the presence or absence of adequate understanding of each M-CHAT-R/F item (yes, no, or equivocal). Caregiver responses to M-CHAT-R/F items were additionally categorized as (1) ‘concerning’ or ‘non-concerning,’¹ and (2) ‘with understanding’ or ‘without understanding’ of the item’s intent.² These responses were compiled and used to determine overall acceptability of the Nepali translation for each M-CHAT-R/F item. Frequencies and percentages of caregiver responses (‘concerning’ or ‘unconcerning’) and caregiver understanding (‘with understanding’ or ‘without understanding’) were calculated using Microsoft Excel 2010 software.

Results

In total, 13 children of Nepali-speaking Bhutanese caregivers were screened using the Nepali M-CHAT-R/F; all were between 17 and 26 months old (Table 1). All caregivers who were interviewed were of Bhutanese origin and identified Nepali as their native language. Many caregivers reported speaking some English, and two caregivers reported being bilingual. Caregiver education level ranged greatly, from completion of grade three in Nepal, to US graduate students.

Throughout all patient interviews, 5 of the 20 M-CHAT-R/F items elicited ‘concerning responses’ (i.e., responses that suggest ASD risk) from caregivers. The majority of M-CHAT-R/F items were understood by caregivers. However, there were multiple items in which one or more caregivers demonstrated poor understanding of the questions’ intent

¹Note that “concerning responses” refer to M-CHAT-R/F responses that suggest risk for ASD.

²Caregiver responses that were determined to reflect ‘equivocal’ understanding were coded as ‘without understanding.’

(Table 2). A total of five of these poorly understood items were also items in which caregivers gave answers concerning for ASD (Table 3).

In total, four items of the M-CHAT-R/F required revision (Table 4) to better improve clarity of the item, as well as understanding among caregivers. Two of these items were revised prior to the start of screening based on interpreter expertise. The remaining two items were revised at the project's midway point, as they were found to cause confusion among caregivers during the screening process (i.e., caregivers asked for clarification or repetition of item and/or commented that the item was difficult to understand). It should be noted that Item 12 was not revised despite being misunderstood by 15% of caregivers, as well as having the second highest number of "concerning responses." Based upon the authors' discussion with the interpreters regarding this item, the authors felt that some caregivers were hesitant to answer the question negatively (i.e. "no, my child does not get upset by everyday noises") as several of the preceding items had been answered in the affirmative. Furthermore, when the interpreter restated or clarified this item, caregivers would often then provide an unconcerning response; however, the caregivers' first response was documented, thus contributing to the number of "concerning responses" that were recorded. Among the two caregivers who were determined to have misunderstood the question one requested clarification regarding "inside" versus "outside" noises, while the second caregiver was unable to restate the item in her own words. Based on this information, the authors did not feel that this item warranted a revision.

Caregiver Interviews

When asked why doctors incorporate the M-CHAT-R/F into patient visits ("Why do doctors ask these questions?"), most caregivers believed the doctor was determining if the child was growing and maturing appropriately. When then asked to describe the term 'child development' in the caregiver's own words, two issues arose. First, we learned that no comparable word exists for the phrase 'child development' in the Nepali language. As a result, the interpreter described the process of child development (i.e., the child growing...) to the caregiver before he/she could then answer the question. Two caregivers stated that they did not understand the questions. Other caregivers used the term 'milestone' or described the process of a child growing and changing as they age. Another caregiver stated that child development means that the child should be growing mentally, physically and intellectually. Most often, however, caregivers described a child's physical growth process as an indication of overall child development.

We found that only two caregivers were familiar with the term 'autism' and were subsequently able to briefly describe their understanding of the disorder. These two women were employed by a local day-care facility and had completed employee training on recognizing ASD signs through their places of employment. One caregiver had heard of the term "autism," but could not describe it. The remaining 10 caregivers had no knowledge of ASD.

Discussion

M-CHAT-R/F Screening

Thorough translational and educational efforts, although time-intensive, are critical for producing culturally-appropriate, valid materials used for screening and increasing ASD awareness among vulnerable populations, such as pediatric Bhutanese refugees and their caregivers. We found that almost all of the interviewed caregivers (80%) had poor understanding of at least one M-CHAT-R/F item. In fact, the two M-CHAT-R/F items that were most frequently misunderstood (Q1 & Q5)³ required revisions to produce a more easily understood version of the M-CHAT-R/F. This illustrates the necessity of appropriately adapting medical screening tools such as the M-CHAT-R/F and improving caregiver knowledge of child development. Without undergoing a thorough adaptation process, screening instruments and questionnaires are at risk of contributing to caregiver confusion and misunderstanding of the questions' intent. Without appropriate comprehension, both physicians and caregivers may be misled when determining a child's risk of ASD. The implications of this—either a false positive or a false negative—directly affect the health-care of a child and may subsequently place strain on the family, community and medical system.

The newly adapted Nepali M-CHAT-R/F provides clinicians who care for children of Nepali-speaking caregivers ages 16–30 months with an adapted and translated ASD screening tool; while the tool has not yet been validated against a gold standard instrument, it can give the clinician an idea of whether developmental concerns may be present. This Nepali M-CHAT-R/F will help facilitate ASD screening in Nepali-speaking refugee children who are cared for in clinics similar to the DCRPC across the United States, as well as in clinics in other countries caring for Nepali-speaking refugees.

Additionally, we have provided a description of our methods, adapted from those of the WHO, for those seeking to replicate the process of M-CHAT-R/F adaptation. There are numerous resources to guide the translation and adaptation of medical materials. However, this wealth of information could quickly become overwhelming; therefore, a comprehensive, standardized guide for translation, such as the one created by practitioners at the Research Institute at the Children's Hospital of Philadelphia [19], would be immensely useful to the medical and public health communities. We hope that our methods will serve as the basis for a potential guide for those adapting similar materials.

Culturally sensitive translations of medical materials like the M-CHAT-R/F are vital for providing timely and comprehensive pediatric care for refugee populations such as the Bhutanese community in DeKalb County, Georgia. A thorough translation process is necessary to ensure both the appropriateness and clarity of the M-CHAT-R/F items. This is especially important, as our surveyed Nepali-speaking caregivers had little existing knowledge or awareness of ASD, and therefore more potential misunderstanding of why the M-CHAT-R/F might be administered. Medical providers caring for these patients should be

³Question 1: If you point to something across the room, does your child look at it? Question 5: Does your child make unusual finger movements near his or her eyes? (For example, does your child wiggle his or her fingers close to his or her eyes?)

aware of possible knowledge deficiencies regarding child development and should continue to educate caregivers on child development and developmental disorders, such as ASD. Future validation studies of this ASD screening tool are needed if robust clinical and epidemiologic research regarding ASD in this population is to occur. Research which aims to further understand the refugee community's knowledge of child development and developmental delay (for example, the manifestations of developmental delay that warrant medical attention) would contribute greatly to the medical community's ability to care for this population.

Caregiver Understanding of ASD and Child-Development

We found that with few exceptions, most Bhutanese caregivers had a limited or non-existent understanding of the terms 'autism' or 'autism spectrum disorder.' This lack of knowledge regarding ASD is not surprising, as there is little awareness of ASD in the caregivers' county of Nepal [20, 21]. Additionally, we found that most caregivers simply described physical development as a marker for 'child development.' These findings are in keeping with recent literature demonstrating minimal understanding of developmental milestones and developmental disabilities among refugee caregivers [9]. This is especially important information for pediatricians who are tasked with monitoring all aspects of a child's physical, emotional, social and educational development, much of which is done through parental report. Lack of parental education regarding typical child development and/or early signs of developmental delay should be addressed by healthcare providers and public health practitioners so that refugee caregivers can improve their understanding of the many dimensions of child development. Further research is needed to learn which words refugee caregivers typically use when speaking about the aspects of their child's physical, emotional and cognitive development. Understandably, this information would likely be immensely helpful for practitioners caring for refugee children. For now, we suggest the following as an example of what a healthcare provider might ask a caregiver regarding child development: *"Children grow in many ways. For example, they grow physically, mentally, and emotionally. Do you have any questions about how your child is growing physically, growing mentally or growing emotionally?"* It is also important to note the role that healthcare interpreters play in patient interviews. For example, if an interpreter is translating "child development" into "child growing," then the healthcare provider may be unable to thoroughly assess the child's overall progress. It may be important, then, for clinics which utilize onsite interpreter to implement periodic trainings regarding basic healthcare topics, such as child development.

Provider awareness of the health needs specific to refugee children continues to increase; however, at the present time there are large disparities between the care provided for US born children and refugee/immigrant children [22]. For example, many of the standardized and validated developmental screening instruments are not yet translated into the languages commonly spoken in the homes of refugee children. As developmental screening (including screening for ASD) has become the standard of care for children in the United States, the medical and public health communities should develop appropriate, validated screening instruments for children among minority ethnic and language groups.

Strengths and Weaknesses

Our project incorporated feedback from multiple caregivers ($n = 13$) regarding their understanding of various M-CHAT-R/F questions and their suggestions for improvement of grammar and syntax. To our knowledge, this is the most robust study to date in terms of methodology for assessing the cultural appropriateness of an ASD screening tool among the Bhutanese population. However, our study included only a convenience sample of Bhutanese refugee children and caregivers seen at the DCRPC. Thus, our results are specific to this population of Nepali-speakers and therefore cannot be generalized to the larger Nepali-speaking population.

Our project utilized sub-sections of the translation protocols suggested by various groups [23] for the translation and adaptation of the validated M-CHAT-R/F ASD screening tool. Our aim was to most closely follow the previously mentioned WHO protocol. However, the WHO protocol includes a bilingual expert panel to complete a back translation of instrument following its initial forward translation. Because our expert panel was limited in its bilingual speakers, this step was not feasible in its entirety.

There are several limitations to our study. First, the study included a small sample size ($n = 13$), with a disproportionate representation of male ($n = 5$) versus female ($n = 8$) children. This is especially important as ASD has a significantly higher prevalence among males versus females [24]. Secondly, the WHO recommends that, during the process of translation and adaptation of materials, pretest material should be compiled by an expert panel of bilingual speakers [18]. However, our pretest material was compiled and later edited individually by two separate Nepali interpreters. Lastly, the WHO recommends that the pretest of translated materials be given to a minimum of 10 persons for each section (for example, caregivers of males and females) [18]. As previously noted, the M-CHAT-R/F follow-up questions, which are utilized in the event of a positive screening with the M-CHAT-R/F questionnaire, did not undergo multiple rounds of translations as did the M-CHAT-R/F screening questions. Instead, it underwent forward translation only. This was due to time limitations of caregivers and well as our interpreters and translator. Ideally, the follow-up questions would have undergone the similar adaptation process.

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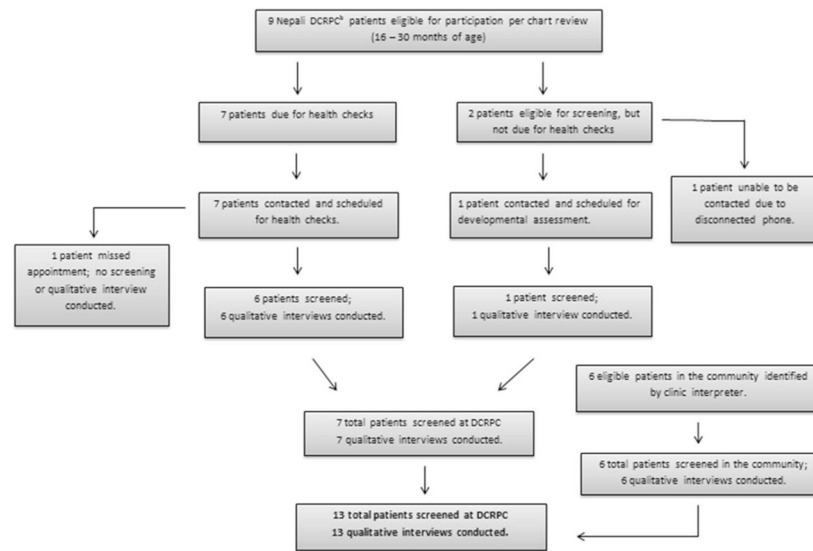


Fig. 1.
Bhurmese caregiver and patient recruitment process for M-CHAT-R/F screening and
adapation. M-CHAT-R/F: Modified Checklist for Autism in Toddlers, Revised with Follow
Up. DCRPC: DeKalb County Refugee Pediatric Clinic

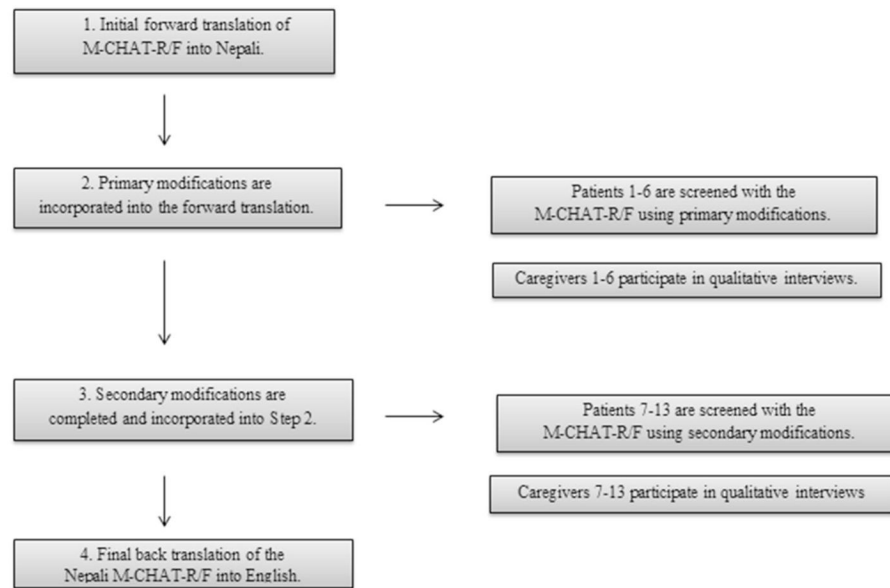


Fig. 2.
Overview of study design

Table 1

Sociodemographic characteristics of participants

| Demographics and clinical characteristics | |
|--|------------------------------------|
| Sex, n (%) | |
| Male | 5 (38.5%) |
| Female | 8 (61.5%) |
| Age, months | |
| Patient mean age | 21.9 |
| Age range | 17–26 |
| Education level, grade (range) | |
| Maternal caregiver education level | 9 (3rd grade—US graduate student) |
| Paternal caregiver education level | 10 (8th grade—US graduate student) |
| Number of months in US, month (range) | |
| Patient | 16.5 (4–26) |
| Caregiver | 28.7 (4–60) |
| Number of children in family, n (range) | 1.5 (1–3) |

Table 2

M-CHAT-R/F items in which caregivers had poor understanding of question's intent

| M-CHAT-R/F Item | M-CHAT-R/F Question | No. of Caregivers who did not understand question intent (%) |
|-----------------|--|--|
| Question 1 | If you point at something across the room, does your child look at it? (For example, if you point at a toy or an animal, does your child look at the toy or animal?) | 3 (23.1) |
| Question 3 | Does your child play pretend or make-believe? (For example, pretend to drink from an empty cup, pretend to talk on a phone, or pretend to feed a doll or stuffed animal?) | 1 (7.7) |
| Question 4 | Does your child like climbing on things? (For example, furniture, playground equipment, or stairs) | 1 (7.7) |
| Question 5 | Does your child make unusual finger movements near his or her eyes? For example, does your child wiggle his or her fingers close to his or her eyes? | 4 (30.1) |
| Question 9 | Does your child show you things by bringing them to you or holding them up for you to see – not to get help, but just to share? For example, showing you a flower, a stuffed animal, or a toy truck | 1 (7.7) |
| Question 12 | Does your child get upset by everyday noises? (For example, does your child scream or cry to noise such as a vacuum cleaner or loud music?) | 2 (15.4) |
| Question 15 | Does your child try to copy what you do? (For example, wave bye-bye, clap, or make a funny noise when you do?) | 1 (7.7) |
| Question 16 | If you turn your head to look at something, does your child look around to see what you are looking at? | 1 (7.7) |
| Question 17 | Does your child try to get you to watch him or her? (For example, does your child look at you for praise, or say “look” or “watch me”?) | 2 (15.4) |
| Question 19 | If something new happens, does your child look at your face to see how you feel about it? (For example, if he or she hears a strange or funny noise, or sees a new toy, will he or she look at your face?) | 1 (7.7) |

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Table 3

M-CHAT-R/F questions with both concerning responses and lack of caregiver understanding

| M-CHAT-R/F Question | M-CHAT-R/F Question | No. of 'concerning responses' prior to M-CHAT-R/F revision | No. of caregivers with poor understanding of question's intent | Question changed by interpreter at revision point? |
|---------------------|--|--|--|--|
| 5 | Does your child make unusual finger movements near his or her eyes? (For example, does your child wiggle his or her fingers close to his or her eyes?) | 5 | 4 | Yes |
| 12 | Does your child get upset by everyday noises? (For example, does your child scream or cry to noise such as a vacuum cleaner or loud music?) | 4 | 2 | No |
| 15 | Does your child try to copy what you do? (For example, wave bye-bye, clap, or make a funny noise when you do?) | 1 | 1 | No |
| 17 | Does your child try to get you to watch him or her? (For example, does your child look at you for praise, or say "look" or "watch me"?) | 2 | 2 | Yes |
| 19 | If something new happens, does your child look at your face to see how you feel about it? (For example, if he or she hears a strange or funny noise, or sees a new toy, will he or she look at your face?) | 1 | 1 | No |

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Table 4**Final Revisions to Nepali M-CHAT-R/F**

| Original | Reason for change(s) |
|--|---|
| <p>Introduction</p> <p>Please answer these questions about your child. Keep in mind how your child usually behaves. If you have seen your child do the behavior a few times, but he or she does not usually do it, then please answer no</p> | <p>The term “behavior” may not be understood by caregivers with low literacy level. The word was changed so that the sentence reads: “If you have seen your child do the things below a few times, but he or she does not usually do it, then please answer no”</p> |
| <p>Question 1</p> <p>If you point to something across the room, does your child look at it?</p> | <p>The Nepali word for “something” may be interpreted by those from rural regions as “cattle.” The word was changed to a more generic word for “thing” that will be more universally understood</p> |
| <p>Question 5</p> <p>Does your child make unusual finger movements near his or her eyes? (For example, does your child wiggle his or her fingers close to his or her eyes?)</p> | <p>The word “unusual” was found to be an unfamiliar word for many Bhutanese caregivers. The word was changed to mean “strange” or “odd”</p> |
| <p>Question 17</p> <p>Does your child try to get you to watch him or her? (For example, does your child look at you for praise, or say “look” or “watch me”?)</p> | <p>The literal translation of this item (including the example) was found to be quite long, and was shortened for ease of translation. The shortened translation maintained the item’s original meaning</p> |

The Introduction and Question 1 were revised prior to the start of screening. Questions 5 and 17 were revised after the project’s midpoint M-CHAT-R/F: Modified Checklist for Autism in Toddlers, Revised with Follow Up